

## PHD BY PUBLICATION

### **Towards a social model of disability; challenging disability discrimination in adult nursing**

Scullion, Philip

*Award date:*  
2010

*Awarding institution:*  
Coventry University

[Link to publication](#)

#### **General rights**

Copyright and moral rights for the publications made accessible in the public portal are retained by the authors and/or other copyright owners and it is a condition of accessing publications that users recognise and abide by the legal requirements associated with these rights.

- Users may download and print one copy of this thesis for personal non-commercial research or study
- This thesis cannot be reproduced or quoted extensively from without first obtaining permission from the copyright holder(s)
- You may not further distribute the material or use it for any profit-making activity or commercial gain
- You may freely distribute the URL identifying the publication in the public portal

#### **Take down policy**

If you believe that this document breaches copyright please contact us providing details, and we will remove access to the work immediately and investigate your claim.

# **Towards a Social Model of Disability; Challenging Disability Discrimination in Adult Nursing**

**Philip Andrew Scullion**

**PhD**

**Coventry University**

**Submission of amendments following viva voce**

November 2010

# **Towards a Social Model of Disability; Challenging Disability Discrimination in Adult Nursing**

## **Abstract**

This portfolio examines, contextualises and evaluates the contribution of six selected publications focussed on the social model of disability and discrimination within adult nursing in the UK. The publications all appear in peer reviewed journals and trace a developing understanding of the concept 'disability', recognition of the impact of discrimination and the role that nurses play in sustaining this situation. It develops the idea that a shift towards the social model of disability will be instrumental in challenging disability related discrimination. Implications for adult nursing are examined including the potential of social advocacy and the need for a closer relationship between nursing studies and disability studies. The contribution to the knowledge base is unique in the context of adult nursing suggesting that embracing the social model may facilitate a legitimate contribution to the aims of the disability movement. A framework is developed for the evaluation of the contribution of the submitted papers using the concepts; Model of disability, Interests being served, Non-exploitative approaches and Challenging disablism by extensive dissemination [MINC]. The portfolio draws on many more than the six submitted papers in demonstrating an extensive dissemination strategy. The complexity of the concept of disability and the role of nurses in disability research is explored and critiqued. Contemporary critical theory is drawn on as an epistemological base combining critical analysis and reflexivity with empirical procedures. It concludes with tangible links into future developments of this body of work in championing the need for challenging discrimination and the potential use of the social model as a valuable tool in moving towards this goal.

## Contents

Introduction	3
The nature of the problem	5
Overview of selected papers	7
Epistemology	11
Legitimacy of nurses engaging in disability research: A reflexive critique	18
Evaluation of the contribution of submitted papers	24
Critical applications to adult nursing	37
Future developments of this work	43
Limitations	47
Conclusions	48
References	50
Appendices	54-69

1. List of six selected publications used as the basis for this portfolio
2. Comprehensive list of disability-related publications by this author  
excluding the six selected for this portfolio
3. Hard copies of six publications selected for this portfolio
4. Questions to be considered in relation to disability research
5. Citations of selected publications
6. Table 6 Elegant Challenging from Thompson 1998
7. Indicators of Esteem

## **Introduction**

This portfolio comprises a selection of six single authored publications which demonstrates personal and academic development around the theme of models of disability and discrimination within adult nursing. It provides a unique contribution to knowledge which challenges the existing disability paradigm (these publications are listed in Appendix 1). This document links these elements and offers a critical evaluation of the portfolio. It is set in the context of other outputs by the same author (See Appendix 2), along with the work of disability scholars and nurse researchers. An expanding UK legal framework, designed to provide UK citizens with protection from, or at least legal redress for, disability related discrimination, provides a backdrop. This coincides with disturbing official reports cataloguing systematic negative discrimination and abuse of disabled people within healthcare settings (Scullion 2009). While recognising the complexity of the issues surrounding disability within nursing, it is argued that a social model of disability should be acknowledged as having a key role in addressing disability discrimination. Currently little known within general adult nursing and in spite of its incomplete representation of disabled citizens, the social model of disability has considerable potential to influence adult nursing in creating a challenge against disability related discrimination.

What is argued therefore is that a paradigm shift in conceptualising disability away from the dominant paradigm in the direction of the social model of disability is necessary in view of the discrimination disabled people face. Furthermore it is argued that a critical application of this paradigm shift

suggests that nursing and nurses may become part of the disability movement by challenging discrimination faced by disabled citizens.

This portfolio seeks to establish the nature of the problem of disability discrimination in relation to nursing before providing an overview of the selected publications. Intellectual growth of the author is traced leading to an epistemological stance grounded in critical theory which provides the basis for a key academic role in this field straddling elements of both adult nursing and disability studies. Following this a reflexive critique of the role of professional nurses in disability related research is presented. It is then argued that a unique contribution to knowledge is made by challenging the damaging medicalised paradigm of disability which is evidenced within adult nursing in the almost unquestioned view that 'disability' simply equates with illness. Beyond challenging this harmful view by presenting a more positive view based on the social model, the potentially liberating role of adult nursing is expounded and the contribution to knowledge is extensively disseminated. While the social model of disability is critiqued it is argued that it retains sufficient credibility and a radical edge as to be invaluable in adult nursing where its recent appearance has novelty value, but of much greater significance it enables 'disability' to be viewed as a social justice and rights issue. The contribution is critically judged, partially on the basis of criteria drawn from the literature and in part by the level and nature of the challenge presented. Critical applications to the field of adult nursing are examined with a focus on an emerging theme related to advocacy. The challenge is to discrimination related to adult nursing and beyond. It is essentially a desire

for indirect research utilisation “involving changes in nurses’ thinking” (Polit and Beck 2010;39), specifically around the concept ‘disability’.

This synthesis amounts to an argument for a cautious paradigm shift in the direction of the social model of disability as one key strategy in challenging disability related discrimination which prescribes a key role for nurse education.

### **The nature of the problem**

The submissions, some of which consist of research reports while others present critical analyses, draw on the extensive literature of academic papers and official reports indicating that disabled people, though large in number, form a vulnerable minority group subject to various kinds of discrimination, if not oppression. Pfeiffer (2003) points out that evidence from studies which cross national, cultural and ethnic boundaries shows consistently that to be disabled is to be negatively categorised and associated with poverty, lower standards of education, limited life chances and poorer health and access to healthcare compared to non disabled people. At a recent disability studies conference, Sandén (2007) contended that “disabled people to a great extent perceive themselves as belonging to a forgotten sector of society in that they experience administrative barriers, shortcomings in the way individuals and institutions behave towards them, institutional discrimination, being socially dead, etc”. However it is highly questionable to assume that the majority of

disabled people actually view themselves as disabled, even some immersed in disability rights organisations (Beckett 2006). The perception of oppression may therefore relate only to a politicised minority, however the experiences described by Sandén's (2007) are widespread and confirmed by an extensive literature base (Swain 2006; Vanhala 2006; Smith 2005; Thomas 2004; Priestley 2003; Buzio, Morgan and Blount 2002; Gallagher 2001; Barnes 1992).

In relation to healthcare settings, those cast in a patient role may be inherently vulnerable. However, when disability is an added dimension, then such citizens as patients face further discrimination. In just the sort of environment where one may expect a safe haven of disability-friendly attitudes (Harrison 1999), disabled people actually face poor access to primary care, denial of treatments, human rights violations, lack of dignity and a medically dominated socialisation process which leaves those with acquired impairments accepting that their problems almost entirely stem from their own dysfunctional bodies or minds (Bowers 2003; Brett 2002; Carter and Markham 2001; Harrison 1999; Northway 2003; Scullion 2000a). This hardly represents the intentions or perceptions of most nurses and other medicalised professionals, who in general do not set out to harm patients nor deliberately discriminate against those patients who happen to be disabled. The helping professions are however inadvertently disabling in their approach and effect largely because their thinking about disability reflects the societies they are drawn from (Swain and French 2001;751). These in turn, though rarely explicitly expressed, hold that many disabled people are 'non-persons' and are thus not to be afforded



full citizenship status reflecting an attitude that their lives are not worth living (Singer 1994, Gallagher 2001). Denial of human rights is however not perceived as such since some disabled people are not seen as full members of society (Scullion 2008). Dwyer (2004;115) examined the concept of citizenship and concluded that "Citizenship rights for disabled people remains firmly anchored in rhetoric rather than reality". This negative disablist thinking presents disability as a non-issue in the realms of social justice or equal opportunities, perhaps particularly in the mind set of health professionals, which is steeped in a biomedical model.

### **Overview of selected papers**

The range of work selected spans the period from 1999 to 2010 (Copies are located in Appendix 3) but the interest and publications alluded to in this portfolio commenced much earlier. Each paper has been accepted for publication in peer reviewed journals and they are linked by a growing understanding of the concept of disability and a consistent thread relating to advocacy which is more evident on retrospective analysis.

The first of these papers, published in the 'Journal of Advanced Nursing', an international journal, concentrates on conceptualisations of disability reporting a study involving student nurses and their teachers. How an issue is conceptualised will determine both individual and corporate responses giving this central importance when examining disability within a healthcare setting.

Indeed the findings, in keeping with the dominant medicalised paradigm, whereby medicine has enormous institutional power in modern society (Turner 2008;176), are the subject of sustained challenge over the following decade as outlined in this portfolio. This paper from 1999 concluded that nurses need to change to become 'potential allies in the promotion of equality' as opposed to perpetuating social oppression.

The second paper, published in 'Disability and Society', a high quality international journal, focused on examining a nursing curriculum and the ways in which the topic of disability was addressed at the stage of preparing people to enter the nursing profession. It showed that disability as a form of social oppression was an alien concept within adult nursing. Health professionals exert a considerable impact on people who have recently acquired impairments during a transitional period, many of whom will become 'disabled people'. However, within this curriculum, teachers' main objective was to develop 'empathic awareness' within their students and their teaching methods did not challenge discrimination.

Paper three, published in 'Nursing Standard', a weekly nursing journal with a large audited readership, reports a small survey examining student nurses' definitions of disability. It acknowledges that the suggestion that nurses could be implicated in discriminating against disabled patients would most likely be seen as preposterous. This is subject to examination of possible intricate links to the findings that a large majority of respondents defined the concept 'disability' in medicalised ways in line with other studies. This paper draws out

implications based on the deduction that the medical model fails to challenge behaviours or policy and suggests that a social model offers nurses a new and attractive perspective on disability and argues that its potential role in tackling discrimination deserves greater recognition.

The fourth paper provides an analysis of the role of nursing curricula in dealing with disability as an equal opportunity issue. It was published in the international peer reviewed journal, 'Nurse Education Today'. While it is acknowledged that equal opportunity issues have some influence in nursing, disability struggles for recognition as an equal opportunity issue and this paper argues that such lack of recognition is a missed opportunity to mobilise nurses "as potential advocates with disabled people" (Scullion 2000b;199).

Based on an analysis of; the role of curricula, the fact that nursing is implicated in disability discrimination and the finding that there is very little commitment to the social or equality dimensions of disability within adult nursing, an argument that nursing cannot be neutral on this issue strongly suggests that nursing curricula should be utilised to challenge disability discrimination.

The fifth paper, published in the 'British Journal of Nursing', addresses a wide readership in arguing that nursing, and education in particular, should rigorously address its responsibilities in relation to disability discrimination. Specifically this paper suggests that nurse education should aim to ensure positive images of disabled people are promoted to clients, colleagues and the public in an attempt to challenge negative values and stereotypes. Legal

responsibilities did not at the time extend to requiring public bodies to promote positive attitudes however the philosophical concepts giving foundation to these pleas were professional, moral, commitment to health and well being in general and to individual clients in particular, along with reference to social justice.

The sixth paper, again in the anonymously peer reviewed international 'Journal of Advanced Nursing', was accepted for publication in 2009 and published the following year. It acknowledges that Disability Discrimination remains widespread, adult nursing has had limited involvement in challenging this situation and earlier calls to address this remain largely unheeded.

The instrumentality of a social model of disability in enhancing nurses' role in "challenging disability discrimination at both patient and societal levels" (Scullion 2010a;3) is examined. Models of disability are not uncritically accepted. The limited but growing appearance of the social model in nursing literature is examined and the potential for a merely surface acceptance is analysed, whereby terminology changes but not the underlying beliefs. In spite of the limitations of the social model it is argued that it has, as yet unfulfilled potential to promote disability equality within nursing and through its influence, beyond the clinical to the social context. The notion of advocacy and in particular social advocacy is more explicitly examined as an overarching theme which links the previous papers as a key critical application of the social model to adult nursing.

## **Epistemology**

It is the contention in this body of work that the generation of knowledge does not take place in a vacuum nor is it a politically neutral activity since “all thought is fundamentally mediated by power relations that are social and historically constituted” (Kincheloe and McLaren 2005;304). Contemporary social relationships are not equally balanced; the case of disabled people provides a prime example of this with them being void of privilege in comparison to the rest of society and the medical establishment in particular. The comparatively privileged social position enjoyed by medicine and other professions runs parallel to the privileged position enjoyed by the dominant research paradigm on which these professions are largely based. Positivism presupposes primacy and a privileged researcher stance over the researched and since it is thus the legitimate ‘way of knowing’ it prevents some important questions from being considered; questions which are critical of the status quo. Rather than uncritically accepting the claims of scientific objectivity, a critical theory stance has been adopted for this body of work.

Prior to the commencement of this work I would more readily have subscribed to the scientific stance in seeking single truths about disability, however this has been challenged and modified by exposure to and engagement with the evidence emerging from disabled people and related philosophical debates. I have noted first hand that without a comprehensive understanding of the concept ‘disability’ informed by critical analysis, accepting positivism as the only legitimate form of knowledge generation contributes to, rather than challenges, disablism. Positivism or merely quantitative data alone is deemed

to be “unable to describe the social construction of reality” (Morrow and Brown 1994;202) which is what is required here. For example, examining attitudes via an established quantitative Likert scale (Yuker et-al 1960), critiqued in paper one, perpetuates negative images of disabled people. It asks respondents to declare their opinion on the assertion that ‘Disabled people are often unfriendly’. However this is not balanced within the scale by a corresponding question about the perceived ‘unfriendliness’ of non-disabled people. This provides one example of what Porpora (2005;262) describes as the mistake of conflating evidence with explanation rather than taking statistical data as “evidentiary tools, enabling assessment of explanations”.

The challenge of claims that medicalised professionals are ‘instruments of devaluation’, and associated assertions that nursing is discriminatory in its dealings with disabled people demands an evaluation of the evidence base for such claims. Sources of evidence based on an adherence to the social model in particular present just such a picture of disability discrimination implicating health professionals. This began to have resonance with this author’s understanding of the relationship between disabled people and adult nursing. Subsequently this study determined to check this reading of the situation using pragmatic methodological pluralism in line with a critical theorist stance that no specific methodology or theory “can claim a privileged position that enables the production of authoritative knowledge” (Kincheloe and McLaren 2005;311).

While knowledge emerging from a philosophical stance of logical positivism is not rejected as illegitimate in many areas of nursing and medicine it is acknowledged that the very research questions posed, the data collection questions and methods employed, set in a one-way street of power relations, may all be tainted by widespread disablism and may result in a distorted or, at best, partial portrayal of truth. Adopting a realist stance however, the need for an interpretive dimension in examining social relations becomes apparent. On its own, knowledge emerging from the naturalistic paradigm is similarly incomplete but arguably less likely to result in damaging distortions of the situation of disabled people's lives and experiences within healthcare. Taking disability as a socially constructed and subjective concept, as depicted by the social model, then a critical epistemology, acknowledging the value of both qualitative and quantitative data is more appropriate.

Critical theory tends to conceptualise the familiar qualitative quantitative divide as less appropriate than focusing on intensive (in-depth) and extensive (involving large numbers) research strategies and attempts to mediate between these polarised positions (Morrow and Brown 1994). The legitimacy of the conflation of reflexivity and empirical procedures is therefore unproblematic. While there is an acknowledged affinity between critical theory and methodological strategies such as case study, participatory action research, ethnography and historical research, many of these designs employ methodological pluralism. An explicit acknowledgment in this project as it has developed over time is that research is not neutral and the processes of generating and dissemination knowledge are influenced by the researcher. It

concur with the feminist epistemology which argues that the process is overtly political, and personal experience is valued (Swain, French and Cameron 2003;32) and that “values are not irrelevant to the process of knowledge acquisition and verification” (Assiter 2005;243). The critical theory stance legitimises a focus on concerns over the ways social relations mediate power relations in creating alienation and subscribes to the goal of “radical socio-political transformation” (Kellner 1998;7). From early confusion over the role of professional nursing in this field and uncritical acceptance of the hegemony of positivistic knowledge production, I have emerged with a commitment to the generation of knowledge related to disability from within the profession which is open to academic scrutiny, in part achieved via peer review inherent in the publication process and scrutiny by disabled people, yet serving to inform the work of activists based on principles of contemporary critical theory whereby “researchers often regard their work as a first step towards forms of political action that can redress the injustices in the field site” (Kincheloe and McLaren 2005;305). Disability activists in general and champions within nursing who may engage in both individual and social advocacy or other attempts to challenge discrimination, may utilise the knowledge presented within this portfolio in line with an overarching aim of critical theory to “free people from overt and covert forms of domination” (Johnson and Buberley 2003;120), which coincides with the aim of an emancipatory paradigm.

However, in line with the ambiguity felt by nurses over the concept disability reported in papers one and two in particular and as highlighted by Beckett



(2006), analysed in paper six, impairment has significance as one determinant of the life experiences of many disabled people, many of whom call on the medicalised professions for solutions to their troublesome impairments. Here positivism may provide answers in the form of medicalised, psychological, technological, pharmacological or surgical solutions to resolve or mitigate some impairments. Positivism may provide evidence of important correlations or causation of unwelcome impairments and provide some measure of needs via studies showing the prevalence or clustering of impairments. Simply counting can have a positive effect. Knowing for instance the prevalence of multiple sclerosis provides some evidence on which to argue for specialist MS nurses, found to be a valuable resource to those with the disease. While not addressing the various kinds of discrimination faced by individuals with impairments, quantitative research, though not the approach in this work, must not be abandoned if impairment is not to be dismissed as insignificant. Such knowledge is utilized in literature reviews contained within the submitted papers and will continue to have relevance to nursing disabled people in relation to specific problems, e.g. spasticity or pain. Critical theory may however yield useful evidence of the discrimination faced by some people with various kinds of impairments and overall this reflects Beckett's (2006;94) concept of disability allowing for individuals to experience their impairments in the context of a disabling society.

The publications submitted utilise mixed methods including both qualitative and quantitative data using Case Study methodology and Survey. There was much flexibility which embraced the use of semi-structured interview,

documentary analysis, vignettes and questionnaire along with some direct observation and the use of data extracted from a disability discussion forum.

Bearing in mind the constituency which is in need of challenge and change and its predilection for quantitative research, this type of evidence, numerical and statistical, can be used to demonstrate some measure of the size of the problem. The positivistic paradigm can provide valuable evidence to enable the issues to gain a hearing in an environment which is blind to the equal opportunity dimensions of disability. It is at least convenient to be able to quote that around 75% of nurses see disability as predominantly a medical phenomena in such an arena if the collective body of evidence is to avoid “being invisible as unseen by the blind spot of the medicalised disablist world view” (Scullion 2010b;43). Case Study however often uses mixed methods and certainly the semi-structured interviews, yielding qualitative data which was subjected to thematic analysis, provided more in-depth insights into the issues under scrutiny.

In spite of recognition of the potential value of participatory and emancipatory approaches to research, there has not been an explicit adherence to either of these in this body of work although critical theory shares some of their characteristics, such as the desire to generate knowledge and tools to promote social and political awareness and change (Northway 2010). This in part reflects a developing awareness of these approaches on the part of the author and the fact that disabled people have not been the informants.

Nursing students and their teachers have been the main participants.

However there has been a consistent commitment to utilisation and recommendation of literature that has emerged from a participatory or emancipatory paradigm or at least the body of knowledge which reflects the disability movement's general aims.

Tradeoffs and compromises may make the difference between imperfect evidence and none at all. However such compromises may be called for rather less as more 'social model academics' become evident. It may be that within adult nursing emancipatory and participatory paradigms may be less of a hindrance to the progress of research proposals since the Department of Health explicitly asks for evidence of user involvement and the Nursing and Midwifery Council's lead on the 'reasonable adjustments' project came from the disbanded Disability Rights Commission and identifies as a disabled person herself (Kane and Gooding 2009). Priestley's (1997) conclusions about his genuine attempt to engage in emancipatory research are interesting since there was much resistance from the Disabled Peoples' organisation he was working with to the idea that emancipatory research should involve a reversal of the social relations of research production such that the goal became one of equalising rather than devolving power.

This epistemological approach, although evolving over the lifespan of the project, has guided decisions and the process of critical analysis, and while imperfect it provides a critical theoretical basis for the collective presentation and future developments of this body of work.

Evidence which convinces nurses to adopt new thinking about disability based on the social model may itself have a positive impact. Gill (2001;364) argues that adopting social philosophies of disability has an emancipatory impact on individuals' self image suggesting that 'enlightened' nursing may have a liberating effect on clients with acquired impairments. Void of dogmatic adherence to particular methodologies, yet guided by principles of critical theory this portfolio of evidence will be deemed successful if it contributes to the socio-political transformation of the position of disabled people as patients and even as citizens, via the agency of adult nursing by challenging disability discrimination. The dissemination strategy, discussed later, is instrumental in achieving this.

### **Legitimacy of nurses engaging in disability research: A reflexive critique**

Set in the role of oppressor by a proportion of the disability literature, one of the first challenges encountered when I entered this field of scholarship as a professionally qualified nurse, was a personal crisis of confidence and credibility. If I was to take the authentic voice of disabled people, represented largely in the form of academic papers by people who identify themselves as disabled people, my role and legitimacy as a researcher in this area felt immediately undermined. Within a short period of time while working on an early paper which sprang from pursuing my growing interest in 'disability issues', my confidence had evaporated and I was left wondering if my interest and role were little more than an illegitimate voyeuristic intrusion into the very lives of disabled citizens, which solely served my academic career.

Goodall (1995) examined this issue in his paper which was particularly noteworthy since he identified as a disabled person and as a qualified nurse working in education. He focussed specifically on nursing and contends that, in spite of what may appear to be the case based on the social model of disability, nurse education, and of course practice, is relevant and has a role in the lives of some disabled people. Based on the challenge to the medical model, but also criticism of the social model which down-plays the relevance of impairment, he illustrates his position using the example of pain. The lived experience of some disabled people includes both pain and strategies to cope with pain; thus nurse education, and some skills of nurses, become very relevant to the lives of disabled people. Taking disability as “a personal experience of living which daily impinges on, interfaces with, the surrounding environment: it is person-in-society” (Goodall 1995;327), he concludes that disability studies have a place in the nursing curriculum. Furthermore he argues that this should be based on a middle way via what he calls the ‘Interface model’, which could be characterised as the merging of medical and social models incorporating bodily and environmental determinants of disability.

My own acute dilemma over the legitimacy of my roles as a researcher and scholar entering this field of practice, being both a non-disabled person and nurse, were eventually overcome to some extent. Beckett (2006;12), along with others before her (Northway 2000, Stone and Priestly 1996) also faced this dilemma and after much soul searching she concluded that non-disabled people can undertake disability related research “so long as they maintain

reflexivity at all times with regard to their motives, their own identities and their research practices”.

At an early stage in my journey into this field, I examined this issue in a debate stemming from the question ‘who can legitimately engage in disability research?’ (Scullion 1995a). This indicates a cognisance of the need to satisfy at least two major constituencies and the feeling of treading on eggshells since taking sides and acknowledging the underlying politics in research was quite alien to the prevailing research culture of the NHS. The tightrope between nursing and the disability movement presents medicalised researchers with the difficult choice between conceptual frameworks (medical and social models). A potential consequence of this choice may be to bring sharp criticism from the ‘other side’, with implications well beyond the personal discomfort of the individual researcher. If the purpose of such research endeavours is to impact on the thinking of nurses then it will fail unless credibility is established. Equally, disabled people may perceive research as simply compounding their experience of discrimination unless it establishes some credibility within that constituency. This paper was a developmental endeavour for the author grappling with key issues and moving from a position of contentment with benevolent professional led research towards acute discomfort demanding a resolution to the power imbalance. It was presented to an audience of health professionals to encourage debate and enhance political awareness.

Taking the starting point that with professional led research, “society takes cognisance of the opinions of able-bodied beneficiaries’ in preference to the

voice of disabled people” (Scullion 1995a;320), which is mostly unheard but if heard, then unheeded, there appeared to be some merit in this position. If the clients are disenfranchised then respected benevolent health professionals can speak up for them via the research process. Nevertheless the influence of the medical model on the research process, leading to inappropriate questions being posed and possibly inappropriate services being developed, fails to challenge the paradigm which consigns disabled people to a life tainted by discrimination. I was careful to direct criticisms at the “prevailing systems of service delivery and research, which is seen as inherently discriminatory, rather than at individual practitioners” (Scullion 1995a;318), being keen not to alienate them. However, while not recognised at the time of writing that paper, the lack of consultation and exclusion from the research agenda illustrates the core issue; it is *our* research and not *theirs*.

Northway (2000) advocates reflexivity as especially necessary for nurses engaging in what may be viewed as ‘disability research’. She explains three key facets in the process of critical self reflection which attempts to identify the culture and assumptions that influence nurse researchers; the definition of disability being employed, the position of nurses as part of an oppressive system and exploring whose interests are served by the work. In order to encourage researchers and professionals to “keep sight of their role as patient advocate” (Scullion 1995;320) I presented a series of eight questions emanating from a critical social theory perspective (Harvey 1990). (See Appendix 4). These questions are largely captured in the three facets of reflexivity identified by Northway (2000). In line with critical theory which has

a specific focus on domination and questions the social interests served by the generation of knowledge (Morrow and Brown 1994;5), it is essential to engage in reflexivity. The same level of critical reflexive scrutiny should not however be confined to research, rather they should be applied to other types of scholarly endeavours or dissemination which may encourage the utilisation of knowledge however it is generated.

These same considerations are taken up separately by Stone and Priestley (1996), also from the perspective of non-disabled researchers in this field. After setting the context by analysing the social relations of research production exposing 'parasitic' elements, they provide a detailed analytical account of the principles of an emancipatory research paradigm. They resolved the conflict, in part through understanding that "disability status alone does not guarantee emancipatory research" (p13) and concluded that priorities for disability research must be to use the social model, commitment to the disability movement, using non-exploitative methods and wide dissemination of findings to challenge oppression.

The key facets of reflexivity recommended for nurses studying disability (Northway 2000) are combined with the priorities for undertaking disability research (Stone and Priestley 1996) forming a critical framework to evaluate the contribution of this portfolio;

- M-[Model]
  - Definition of disability and use of the social model
- I-[Interests]



- Whose interests are served?: Commitment to the disability movement
- N-[Non-exploitative]
  - Anti-oppressive: Non-exploitative methods
- C-[Challenging]
  - Wide dissemination aimed at challenging oppression

## **Evaluation of the contribution of submitted papers**

The MINC framework is utilised in the following section to determine the value of the original contribution made by this portfolio. The transformative goal of critical theory underpinning this portfolio is examined in the final section, although it is evident within all stages of the framework which consistently challenges the medical paradigm.

### M-[Model]

#### Definition of disability and use of the social model

The submissions presented in this portfolio have alluded to a range of definitions of disability representing, in part, an emerging awareness on the part of the author. The need to declare an allegiance to a definition, while not avoided, was initially unnecessary since the research aimed to discover how nurses viewed the concept 'disability'. Both the medical and social models have been critically evaluated within the papers submitted. While numerous definitions were included these were used as triggers in some of the empirical work to elicit responses from participants and in so doing dominance of the medical model within nursing was exposed. However the medical model has been consistently challenged within the papers submitted and throughout the wider dissemination strategy.

The definition favoured by the disability movement, reflecting the social model, was found to be inadequate by Beckett (2006) in her examination of

citizenship and deemed to be not sufficiently all embracing following its critique in paper six. Beckett (2006;94) argues that a definition needs to allow for simultaneous experience of pain, debility and associated oppression by a disabling society. Her analysis of the limitations of the social model led her to call for an 'embodied' notion of disability and 'realignment between body, self and society'. Many who strive for mainstreaming or normality would not identify with disability culture making disability pride an unappealing notion to many disabled people and 'celebrating difference', "in relation to the lives of people whose impairments are painful, debilitating or even fatal" (Beckett 2006;116) is depicted as overoptimistic or even insensitive. This broader approach is in line with the prevailing notions of individualised and tailored care within the holistic framework of contemporary nursing, and starts where most individuals would, with autobiography (Williams 2001,137). Without undermining the personal identities of clients, some of whom will strongly identify as disabled people, this broader approach may accommodate more people who enter a patient role than the undiluted social model.

Even people with congenital impairment will not automatically identify as disabled as portrayed within a social model, illustrated by a respondent in Beckett's (2006) study who reported that he too had a transition to face in terms of identify since his special school experience fed him with a negative self image and attitudes towards disability. However, Oliver (2009;154) has recently restated that the social model is simply a tool and as such it continues to be strongly advocated by this author as a powerful tool which is suitable for challenging discrimination within adult nursing. This is evident

through the portfolio which gives prominence to the social model which provides an analytical tool in examining disability as an equal opportunities issue, teaching methodologies found and the challenge to the way nurses conceptualise disability. Those nurses who engage in in-depth study will uncover the intricacies and complexity associated with the concept 'disability', necessary for specialist or consultant nurses involved in the fields of rehabilitation, neurosciences and long term conditions but the relative simplicity of the social model and the pressing need to address discrimination makes it an ideal tool for adult nursing and its associated curricula. Its instrumentality and potential in this area are made explicit in the portfolio and an explicit call for a re-examination of definitions of disability "giving particular credence to those favoured by disabled people themselves" (Scullion 2000c;1011-2) confirms the use of the social model as central to the thrust of this work.

#### I-[Interests]

Whose interests are served? Commitment to the disability movement.

As with most publications in academic journals, undoubtedly, the author is likely to be a key beneficiary in terms of kudos, CV enhancement, gaining qualifications, meeting institutional goals or achieving individual promotion. Personal satisfaction may also be considerable. While 'whose interests are served?' is a very legitimate question to enable a critical examination of the value of any contribution, the lure affects people at all levels, including disabled people. In exploring what is portrayed as the recent decline of the disability movement, Oliver (2009;140) points out that even some of its

leaders “opted to put upward personal mobility ahead of the needs of the movement itself” by joining the Disability Rights Commission as employees, interpreted as ‘siding with the establishment’ thus compromising the cause.

Priestley (1997) highlights the pressures on researchers to satisfy a number of groups and is explicit in admitting that in spite of political or philosophical allegiances, it remains “necessary to satisfy academic peers and examiners. For better or worse it is the academy, rather than disabled people at the grass roots, who can pass judgement on a submitted thesis!” Of course a lot of resource is invested in attempts to increase the number of academic staff in Higher Education Institutions who achieve doctoral status; nevertheless the increased opportunities in research which this very status brings may be used to contribute to the aims of the disability movement. Undeniably the author has gained in numerous ways yet there are clear attempts to promote the interests of disabled people as patients and more generally as citizens which are evident throughout this portfolio. There is an explicit commitment to challenging medicalised dominance in thinking about disability, exposing nurses’ contribution to disabling people, introducing the radical concept of disablism to adult nursing, promoting a social construction of disability and a role for nurses in tackling disablism. Disabled people and their organisations are portrayed as key partners in research endeavours and experts about themselves thus legitimating both direct and indirect roles in the nursing curriculum. Collectively the submissions demonstrate commitment to the aims of the disability movement and provide a tentative foundation to build positive applications to adult nursing.

In his updated version of 'Understanding Disability; From Theory to Practice', Michael Oliver (2009) distances himself from the disability movement since he claims it has been hijacked by big charities and Government bodies such as the Disability Rights Commission and its' successor, the Equalities and Human Rights Commission, in rebranding exercises which has diminished control and ownership of its ideas and momentum by disabled people. He calls this "disabling corporatism" (Oliver 2009;171). In place of 'the disability movement' he prefers the term 'the disabled people's movement' for what he describes as "our collective self-organizations" (Oliver 2009;134), in making a firm separatist stance he calls for a renewed commitment to holding disabling corporatism to account. However, in recent research, Sandén (2007) quotes a British Disability Activist;

"One of my worries about the disability movement is that it consists of the public activist, politically organised disabled citizens, in such a way that it effectively silences those who for different reasons do not fit within this model".

The main reference here is to what Oliver terms 'the disabled people's movement' rather than the 'disability movement' or disabling corporatism, offering insight into the exclusivity and narrowness of this version of the 'voice of disabled people'.

In contrast the disability movement has been portrayed as not implying homogeneity but rather a loose collective of organisations and individuals seeking to accomplish social change. According to Beckett (2006;17), in her

work on citizenship, vulnerability and disability, its' various strands are "united in their view that we live in a 'disabling society' in which many people with impairments are socially excluded in a number of ways". This portfolio, in spite of originating from within professional nursing, is clear in acknowledging that nursing operates within and contributes to a disabling society both within the clinical sphere and beyond. Furthermore it is clear on the need for social change and sees nursing as having responsibilities and a growing role in accomplishing such a social change by addressing disability related discrimination. At the risk of being castigated from within the 'disabled people's movement' it is claimed that this portfolio contributes to the wider disability movement and its aim to set issues within a rights and entitlements framework in place of a medical tragedy and charity framework (Bickenbach 2001;565), demonstrating that non-disabled people can, in effect, become a legitimate part of the 'disability movement'. Accepting that the relationship between disabled people and nurses, and indeed other health professionals, may be aptly described as an "uneasy coalition" (Bickenbach 2001;ix) and in spite of Oliver (2009;176-7) warning that, contrary to appearances, nurses are not to be viewed as allies, since they "are the beast itself", it remains possible for nurses to be viewed as part of the disability movement.

#### N-[Non-exploitative]

##### Anti-oppressive: Non-exploitative methods

Commitment to anti-oppressive practice based on the recognition of the position of nurses as part of an oppressive system and its potential role in challenging this situation is partially covered in the previous section

discussing whose interests are served. Key elements from the portfolio are briefly highlighted here however epistemological and methodological approaches to the generation of knowledge are discussed more extensively above.

Where necessary ethical approval was sought and granted and while disabled people were involved mainly indirectly, caution was exercised to ensure that negative stereotypes were not perpetuated. Where vignettes were used as part of the methodology they are factually stated, they provide a social context and were either positive or neutral concerning disability elements. Where disabled people were consulted directly, it was carried out on the basis of equality via a disability research electronic discussion group. There were explicit attempts at championing the aims of the disability movement rather than exploiting disabled people, recommending that disabled people should be welcomed into the profession, arguing that nursing should become familiar with the perspectives of disabled people and promote positive attitudes towards disabled people. The approach was fairly radical in laying considerable responsibility on nursing to become active in challenging disability related discrimination and encouraging alliances with the wider disability movement.

### C-[Challenging]

Wide dissemination aimed at challenging oppression

Critical theory is directed at radical socio-political transformation (Kellner 1998) aimed at challenging disability related oppression and the key role



which nurses can play in this endeavour is the primary focus of this portfolio.

The sort of transformative goal here would result in a society based on equality by exposing and challenging the oppressive features of society and nursing in relation to disabled people, seeking to redirect the attention of nursing from simply recording such social injustice to active engagement in altering it (Carnegie and Kiger 2009). A key stage in the MINC framework in promoting this transformation is widespread dissemination.

The readership of the journals selected for publication, most of which are international journals, is primarily nursing; covering students, managers, practitioners, academics and researchers. The papers submitted are fairly extensively cited over a prolonged period in a wide range of publications, many of which are also international. This may be an indication of the value of the contributions to this body of knowledge and the quality of the journals where these papers were originally published. Crookes (2010) has devised a nursing specific Journal Evaluation Tool and three of the papers are in top ranking journals. Disability and Society, a non-nursing journal, has an Impact Factor: 0.762. An overview of the citation record is provided in the table below (Also see Appendix 5).

Submission	Commentary
<p>Paper One</p> <p>[Journal of Advanced Nursing]</p>	<p>Largely nursing readership and utilised in other papers as part of the wider dissemination strategy. It has been widely cited by at least twenty-two other academic papers, several of which were published in 2009.</p>
<p>Paper Two</p> <p>[Disability and Society]</p>	<p>Explicitly exposing the work to the community of disability scholars and activists. It has been cited at least twelve times by academic papers between 2000 and 2010</p>
<p>Paper Three</p> <p>[Nursing Standard]</p>	<p>Largest weekly UK nursing journal reaching a wide spectrum of nurses and students. This paper has been cited at least fourteen times between 2000 and 2010</p>
<p>Paper Four</p> <p>[Nurse Education Today]</p>	<p>This paper has an international readership specifically made up of key stakeholders in nurse education. It is cited by at least nine others between 2001; most recently 2010.</p>
<p>Paper Five</p> <p>[British Journal of Nursing]</p>	<p>This paper was cited by at least ten academic papers spanning the years 2001-2010. Examines not only the need to challenge discrimination but also the manner in which this is conducted. Citing Thompson's (1998), six characteristics of 'elegant challenging' (See Appendix 6).</p>
<p>Paper Six</p> <p>[Journal of Advanced Nursing]</p>	<p>An international nursing publication which is utilised by senior nurses and those engaged in study. It is often cited although it is too recently published to determine how extensively it will be cited.</p>

Beyond this, achieving wide dissemination aimed at challenging oppression and disability related discrimination required a strategic approach. Two pertinent issues here are the range of publications and the formation of key alliances. Firstly a wide audience of readership has been achieved by targeting a broad range of nursing and other professional and academic journals. The six papers making up this portfolio are published in five separate journals and along with other peer-reviewed papers my work appears in nineteen different journals. Most of these have a readership within nursing where the challenge is directed. Some appear in publications read by disabled people. And while the large majority of these publications are single authored, productive alliances were formed between myself and two colleagues, one of whom worked within the Disability Rights Commission (see Brothers) and the other was a nurse working within the NHS as a Disability Adviser (see Eathorne). Both identify themselves as disabled. As a group, three peer reviewed papers were jointly authored. Other joint publications resulted from collaboration with colleagues including a researcher involved in the Expert Patient Programme, a manager in practice, a manager in education, a specialist nurse (Multiple Sclerosis) and a physiotherapist who identified as disabled. I also commissioned articles from Professor M. Oliver (Professor of Disability Studies), Dr J. Harrison (Royal College of Physicians), and P. Millington with R. Mottram (Coalition of Disabled People) for a journal symposium and a Disability Activist, (C. Lewis) to write a provocative editorial in a professional journal [full details appear in the reference list].

In addition to fourteen peer-reviewed papers on the theme of disability (see Appendix 2) and the six selected for this portfolio, many of which have been widely cited, I have around twenty editorials which often utilise the more substantial outputs presented in this portfolio. These are largely placed in journals read by healthcare and rehabilitation staff including nurses; peppering the literature with anti-oppressive messages. The majority have suggested an advocacy role for nurses and other health professionals and focus on informing readers of issues surrounding disability such as access and discrimination in general and issues related to healthcare systems in particular. They expose barriers, espouse rights and legal responsibilities, challenge negative images and discriminatory language, thinking and behaviours. In effect this series of editorials have presented bite-sized packages of topical information exposing the problem, often drawing on ideas from the social model of disability, explicitly highlighting their relevance to health professionals and arguing to greater or lesser extent for a role tending towards advocacy in challenging disability discrimination. By way of example two of these editorials are outlined below.

‘Oliver asks for more: rejecting illness, neglecting impairment, explaining disability and controlling rehabilitation’ is a two-page editorial which draws on the imagery of *Oliver Twist*’s perceived audacity in asking for an extra helping of gruel from his cruel masters (Scullion 1995b). Oliver; being Professor Michael Oliver, the UK’s first professor of Disability Studies, who was closely aligned to the disability movement and early theorising about disability.

This editorial seeks to distinguish between illness and impairment, challenge health professional's skill level and approach to patients who happen to be disabled people. It introduces and critiques radical social model ideas, originating with the work of Oliver, to a readership of health professionals. Somewhat akin to promoting Oliver Twist to workhouse superintendent, this editorial argues for recognition of disabled people as key partners in designing, delivering and researching health and rehabilitation services. It is somewhat resistant to the view that health professionals have no legitimate role in shaping the future of services, many of which will be for disabled people. A stance which in part reflects this author's dawning realisation of the radical nature of the social model with its inherent challenge to the authority of medicine and related professions. However, its middle of the road tone may well have avoided confrontation and alienation of the very health professionals it sought to influence, arguably making radical ideas more palatable and influential as part of an 'elegant challenge' (Thompson 1998). The piece concludes with; "By all means satisfy Oliver with gruel, but then sit down with him, and be prepared to revise the whole menu" (Scullion 1995b;2), confirming the need for nurses and health professionals involved in rehabilitation to change and work in partnership with disabled people. Based on the social model of disability the notion of asking clients what they want or need was quite radical at that time within adult nursing and perhaps this call represents a first tentative step towards social advocacy.

The second piece is a two page editorial entitled 'Disability equality and human rights: Are clients being empowered or impaired?' (Scullion 2008b),

centred around the United Nations Convention on the Rights of Persons with Disabilities and the newly formed UK Equalities and Human Rights Commission (EHRC). The analysis shows that nation states exhibit different levels of commitment and implementation of the UN convention requirements and even where there appears to be good compliance in a signatory nation, when disabled citizens' attempt to engage with health services they face much individual disruption and many barriers (Goggin and Newell 2005). The UK EHRC; a relatively newly formed collective body, is portrayed as an organisation where disability discrimination is integrated and thus diluted with issues which command greater attention. It allows public bodies; Strategic Health Authorities being cited as an example, to go unchallenged in relation to breaches in disability legislation (the need for Disability Equality Schemes- discovered by a 'Freedom of Information' request made by the author), making this organisation far from robust in championing the human rights of disabled citizens. The editorial concludes by demonstrating how these bodies and issues impinge on health professionals and indeed dictates a key advocacy role;

“If we wish to see a future characterised by fair and equitable access to health care for our clients, as enshrined in the UN Conventions, and which extends beyond their time as ‘rehab patients’, we may have to enter the battleground in partnership with them [disabled people]”  
(Scullion 2008b;2).

Couched in these terms nurses and other health professionals are unlikely to conclude that they desire *unfair* and *inequitable access* since this represents a denial of UN Convention rights for people they currently have a strong

professional relationship with. Furthermore the edict seeks to stretch beyond the scope of that formal relationship, to clients' post-patient, post-rehab existence; health professionals are being urged to accept both individual and social advocacy roles.

### **Critical Applications to Adult Nursing**

The evidence within this portfolio is relevant to nursing and this section will examine its particular relevance as applied to adult nursing and draw out some implications. The theme of advocacy will be examined which has implications for practice and the curriculum. Beyond this, the place of disability studies within nursing is considered before examining future developments.

#### **Advocacy**

Clearly the problem of discrimination is far from being solved. The UK Disabled People's Council, a leading organisation, formerly the BCODP, "passionately believes that the position of disabled people in society is a human and civil rights issue and that society must be changed to allow our full inclusion" (UKDPC 2010). Nursing and its largest division adult nursing, cannot ignore this situation, its role and potential role in contributing towards a solution. The six single authored papers submitted contain a thread relating to the concept 'advocacy'. There are numerous explicit recommendations that, as a logical implication of the situation of disability discrimination found

within society and within nursing, nurses should challenge this by becoming advocates. When nursing and nurses are convinced that they are implicated in creating or at least sustaining discrimination against disabled people, preposterous as this may at first glance seem, they may be motivated to direct involvement in challenging this and promoting disability rights. A key tool to convince nurses will be the social model.

Brandon, Brandon and Brandon (1995;29) point out that nurses "have a long history of advocacy mixed in with oppressive social control", a situation indicative of the fact that 'nursing as advocacy' is no simple solution to disability discrimination. They further argue that the desire to embrace an advocacy role should be viewed with some suspicion since patients may be the pawns in a professional power struggle, suggesting that "nurse advocacy is a new version of 'nurse knows best' and that claiming to be advocates is simply empire building" (Brandon, Brandon and Brandon 1995;36). Much of the literature cites 'self-advocacy' as the gold standard for disabled people often in relation to people with learning disabilities, although this is challenged as impractical by physiotherapists where people have severe communication difficulties (Swain and French 1999). However, as alluded to in the submitted papers, many people with other impairments do not identify as disabled and have no tangible links to organised groupings of disabled people, rendering self-advocacy unlikely at a key stage in the lives of disabled people.

Paper six elaborates on the concept 'advocacy' and utilises the distinction between individual advocacy (a) and social advocacy (A) suggested by



Brandon, Brandon and Brandon (1995). Patients, whether disabled people or not will sometimes benefit from nurses acting as their advocates. This characterises a-advocacy which is common in all types of nursing. A-advocacy however, extends beyond the clinical and individual spheres and is a form of up-streaming. Labelled 'social advocacy' by some nurse writers (Fowler 1989) it is not concerned with individual grievances, but with patterns of problems, difficulties, shortcomings, and possibly with class needs; it may involve "pressing politicians and professionals for better and improved conditions, linked with increased resources" (Brandon, Brandon and Brandon 1995;120).

An illustration from the field of counselling makes the distinction between a-advocacy and A-advocacy explicit. People visit counsellors for a wide range of reasons and some disabled people will use their services for assistance with emotional problems (Swain, Griffiths and French 2006). Yet some of these emotional problems will have their origins in the discriminatory experiences of disabled people. And while it is acknowledged that many people do experience severe debilitating emotional problems, some of which will be categorised as life threatening mental health issues, whereby the full range of professional helps may be necessary, it seems sensible to address the issues 'up-stream' at their source where these can be identified. Some counsellors are beginning to think beyond the therapy couch and along with other tools in their armoury they declare "social advocacy has the potential to be a great instrument of change" (Smith, Reynolds and Rovnak 2009;490). Such change may be aimed at minimising disability discrimination which many

experience as substantially more difficulty to cope with than impairments of various kinds.

Recent research by Llewellyn and Northway (2007) investigated the advocacy role assumed by learning disability nurses, the branch taken to be most active and advanced in relation to addressing discrimination and upholding clients' rights. The extent to which individual nurses embraced elements of an advocacy role appeared to be linked with their conceptual model of disability; suggesting that the fairly recent appearance of the social model may be instrumental in promoting both the necessity and legitimacy of an advocacy role. The role itself was however, almost entirely confined to a-advocacy with only two of nine possible definitions;

- "Proactively getting to know people in the community and encouraging people in the community to get to know people with learning disabilities"
- "Promoting the rights of people with learning disabilities at local and national levels"

...reflecting a role 'beyond the clinic walls', namely A-advocacy.

They found limited support in terms of commitment and priority amongst the nurse participants in this study (Llewellyn and Northway 2007;156) which may indicate that persuading Adult Nursing to assume a social advocacy role will not be easily or rapidly accomplished. Broad dissemination of social model messages targeted at the nursing profession could be viewed as an example of social advocacy since this empowers nurses to mount a challenge to discrimination from within and provides a body of evidence on which to draw.

Lewis (2000;205), a disability activist points out that “many organisations and disabled activists are more than willing to work with professionals or organisations to encourage progress into an inclusive and accessible world where every person is valued equally”, providing an opportunity for nurses to collaborate with disabled people in achieving such goals. While there will be some tension between nurses and their employers in many roles, whereby a-advocacy but not A-advocacy may be deemed legitimate, some nurses will find social advocacy to be compatible with their roles. Specialist and consultant level nurses, for instance those dealing with clients with long term conditions such as MS, Epilepsy or Stroke, will be called on to grapple with policy and have opportunities to influence policy at local and even national level. Awareness of the situation of disabled people in general, and their specific client groups in particular, along with a commitment to challenging discrimination based on the social model, will place such nurses in a position whereby they may exert a positive influence wholly in line with the aims of the disability movement.

Nurse educators also have a role in preparing nurses at all levels to assume responsibilities regarding both a- and A-advocacy with the aim of promoting future self-advocacy (Swain, French and Cameron 2003;148) and within adult nursing they can draw on both Mental Health and Learning Disability colleagues and service users.

### Disability Studies within the Nursing Curriculum

This portfolio reveals that 'disability' as anything other than a medical condition, is virtually absent from the adult nursing curriculum and the mind set of most nurses. In spite of a few recent appearances of the social model within nursing literature (Scullion 2010a), disability as a rights issue remains neglected in the UK. A recent review of psychology concludes that "psychologists need to agitate and argue for institutional changes in order to oppose disabling society" (Goodley & Lawthorn 2006;197) and recommends much closer links between psychology and disability studies as part of a strategy to achieve this transformation. Nursing education should emulate this approach.

Since it is argued that opposing discrimination and social advocacy are increasingly becoming legitimate goals for nursing, a much closer relationship between nursing and disability studies is indicated. In a recent examination of the links between disability studies and nursing studies I point out that they are currently worlds and paradigms apart, as are medicine and disabled people, likewise positive literature and positive actions (Scullion 2010b:37). Some have expressed concern over any merging of disability studies with health professional curriculum (Linton 1998), fearing compromise of the integrity of this young academic discipline, however the need to challenge discrimination should take precedence.

In paper six I further conclude that even with the growing acknowledgement of the social model of disability, positive changes in attitudes or actions may

remain superficial and ineffective. Brandon, Brandon and Brandon (1995;122) conclude that groups such as carers or lobbyist may, at best, form an uneasy alliance with disabled people because they believe different things about the root causes of disability. However, ensuring that 'disability studies' gains entry into the nursing curriculum may well be instrumental in harmonising understandings of the social and equality dimensions of disability, strengthening the contribution of nursing to challenging disability discrimination, as pointed out ;

“Some integration of these disciplines is called for, if disabled people can begin to have confidence that they will gain both equal access to health care systems and fair and equitable treatment from such a system based on full human citizenship” (Scullion 2010b;37).

While there is no single magic-bullet or simple pill for the particular ill of disablism within adult nursing “Disability Studies provides the theory and impetus for the few, but essential, champions within these professions” (Scullion 2010b;40).

### **Future developments of this work**

The six papers selected for this portfolio have already led to a number of further papers and have fed into numerous conference papers and will form the basis of an ongoing series of work. Social advocacy and the feasibility of expanding the involvement of disability studies within the adult nursing

curriculum will be explored via a paper recently accepted for a national disability studies conference.

The Nursing and Midwifery Council commissioned a focussed literature review (Kane and Gooding 2009) based largely on the legal requirement to make reasonable adjustments in the provision of goods and services, including educational services. This review will be read by University personnel responsible for the provision of nurse education and it may positively influence the number of nurses and midwives who are disabled. In contextualising the review, the DRC's formal investigation into the regulation of professionals; 'health' was alluded to suggesting that the good health requirement was likely to lead to disability discrimination. Unsurprisingly, this report points out that although health and disability are different issues, the language used within the NMC's website "tends to couple them together" (Kane and Gooding 2009;5). The review is quite explicit in pointing out that "how disability is understood is critical to challenging discrimination against disabled people and delivering workforces and services that are inclusive, productive and holistic" (Kane and Gooding 2009;17). It goes on to assert that "the social model is a significant challenge to the prejudice and discrimination against disabled people" which is deemed especially useful in countering "exclusionary and prejudicial attitudes" (Kane and Gooding 2009;17). Future work will exploit the 'official' origins of this study in promoting use of the social model. Along with the legal obligation on public authorities, including both the National Health Service and Higher Education Institutions, these influential messages, from the Disability Discrimination Act

(2005) and the Nursing regulatory body will serve as a useful framework to build on the contribution of this portfolio.

Smith, Reynolds and Rovnak (2009) who examined social advocacy from within the counselling professions, point out the very limited research base to support social advocacy and thus advise caution while at the same time recognising the merit of the underlying social cause aimed at emancipation of the oppressed. Similarly adult nursing should engage in further research to highlight ways in which A-advocacy is operationalised and the impact this may have on groups of clients and more widely in society. However there is sufficient evidence and legal warrant to support efforts to utilise the social model, challenge disability discrimination in all its guises and engaging in both a-advocacy and A-advocacy with energy and commitment pending the results of further research. The work on nursing as social advocacy should however be extended with research to uncover examples within adult nursing and the range of advocacy roles nurses assume in order to direct practice in this area. Deficits in educational preparation and organisational support should also be investigated. Research in this area should endeavour to adopt an emancipatory purpose and follow a participatory methodology (Scullion & Guest 2007).

There is scope to extend the dissemination of key messages central to this portfolio by engaging with the profession to identify and generate a critical mass to advance this agenda. Work should be targeted with key groups of nurses such as those involved in public health, long term conditions, and

neurosciences in order to enable and empower those most likely to engage with disabled people. A wide range of networks will continue to be cultivated to promote the champions of tomorrow.

The work will be further advanced by forging relationships with colleagues and institutions involved in disability studies on a platform of shared values and particular interest e.g. Iatrogenic impact of healthcare, models of disability, autonomy of individuals, citizenship, social justice, equal opportunity, values, equality, respect, aesthetics, body image, transitions associated with acquired impairments, service user involvement, long term conditions and the expert patient. The adult nursing curriculum should also extend the coverage of 'disability' as an equalities issue and, avoiding exploitation, promote disabled service-user involvement.

A major project should be undertaken, which explicitly includes adult nursing, following the model found in the recent text by Goodley and Lawthom, (2006) from within psychology. In organising and editing such a book comprising a collection of papers addressing and encouraging the links between nursing and disability studies, the experience from both Mental Health and Learning Disability nursing will be incorporated along with key messages from disabled people. The novel approach of capturing stakeholders' perspectives by providing them with a synopsis of the book and eliciting their feedback, as demonstrated by Swain and French (1999), will be adopted.

The scope of any endeavour is necessarily limited. Numerous other lines of enquiry have yet to be fully explored; many of which could usefully include this



portfolio as a foundational springboard. Some of the gaps in knowledge are outlined below;

- To determine if adult nursing curricula are fit for purpose in meeting the needs of disabled people who become patients
- Comparison of the experiences of healthcare between people who identify as 'disabled' and similar people who do not
- Impact of the social model on thinking and behaviour of qualified nurses
- Role and impact of advocacy and disability equality training on selected groups of nurses
- Impact of nurses' conceptualisation of disability on the transition experiences of people with acquired impairments
- Disability champions within adult nursing

## **Limitations**

While the author can present evidence of professional esteem (Appendix 7), this project is subject to certain known limitations and doubtless others which are less obvious. The project may have matured faster in a conventional approach where a firmer commitment to critical theory and a broader comprehension of the concept 'disability' may have become evident at an earlier stage. Control over the publication process is not entirely with the author, even in single authored endeavours. While errors and omissions which eventually have appeared in print may be the responsibility of the

author, some are not and terminology may be altered without recourse to the author.

While this portfolio may form a platform on which to challenge practice and build change it is not possible to assess its impact on the thinking or actions of nurses nor the experience of disabled people; this will require further studies. Only late in the process did it become clear that the assumption that people with congenital impairments accept the social model- is merely that – an assumption.

There has been a limited role for disabled people to validate this body of work however an attempt was made by exposing the work to disability activists and academics via the publication in *Disability and Society* and a commitment to use the disability literature which may have mitigated this to some extent.

## **Conclusions**

This collection of evidence has made a sustained contribution to the body of knowledge which has examined and challenged the dominant medicalised paradigm of disability operating within adult nursing. It adds considerably to the growing literature which seeks to use the social model as a tool to challenge disability related discrimination and is almost unique in addressing adult nursing within the United Kingdom. It has avoided total conversion to the dogmatism of the social model, particularly in paper six where the model

has been subject to critique, yet maintained a firm commitment to the thrust of its aims as a powerful tool in challenging discrimination.

This portfolio has sought to go beyond such a challenge within adult nursing in supporting a legitimate role for disabled people as professional colleagues and a key role for nurses in advocacy. It argues that a move towards the social model also implies key responsibilities to acknowledge and challenge the wider impact of professionalizing disability by assuming an advocacy role in education, knowledge generation and nursing practice. For adult nursing to arrive at a position of readiness to accept and embrace such roles, represents a giant leap away from the medical model. Simply by challenging nursing in these ways the denial of human rights, exclusion from the profession and much more widely, the perpetuation of negative images of disabled people in society will not halt overnight. However moving towards a social model of disability represents a small step in the right direction. Along with other measures it makes a contribution towards improving the life experiences of disabled people.

## References

- Assiter, A. (2005) Descartes's individualistic epistemology- A critique Chapter 18 pp 240-250 In Lopez, J. and Potter, G (eds.) *After Postmodernism: An Introduction to Critical Realism*. London: Consortium International Publishers
- Barnes, C. (1992) 'Institutional discrimination against disabled people and the campaign for anti- discrimination legislation'. *Critical Social Policy* 12 (34), 5-22
- Beckett, A. E. (2006) *Citizenship and Vulnerability; Disability and the Issues of Social and Political Engagement*. Houndmills: Palgrave Macmillan
- Bickenbach, J. E. (2001) Disability Human Rights, Law, and Policy. Chapter 24 pp565-584 In Albrecht, G.L., Seelman, K.D. and Bury, M. [Eds] (2001) *Handbook of Disability Studies*. Thousand Oaks: Sage Publications
- Bowers, B. Esmond, S., Lutz, B. and Jacobson, N. (2003) 'Improving primary care for persons with disabilities: the nature of expertise'. *Disability & Society* 18 (4), 443-455
- Brandon, D. Brandon, A. & Brandon T. (1995) *Advocacy; Power to People with Disabilities*. Birmingham: Venture Press, British Association of Social Workers
- Brett, J. (2002) 'The experience of disability from the perspective of parents of children with profound impairment: Is it time for an alternative model of disability?' *Disability & Society* 17(7), 825-843
- Brothers, M., Eathorne, V. and Scullion, P. (2002) 'Disability law and employment: what does it mean for staff?' *Residential and Nursing Care* 4(2), 60-63
- Brothers, M., Scullion, P. and Eathorne, V. (2002) 'Rights of access to services for disabled people'. *British Journal of Therapy and Rehabilitation* 9(6), 232-236
- Buzio, A., Morgan, J, and Blount, D. (2002) 'The experiences of adults with cerebral palsy during periods of hospitalization'. *Australian Journal of Advanced Nursing* 19(4), 8-14
- Carnegie, E., Kiger, A. (2009) Being and doing politics: an outdated model or 21<sup>st</sup> century reality? *Journal of Advanced Nursing* 65(9), 1976-1984
- Carter, J.M. and N. Markham (2001) 'Disability discrimination'. *British Medical Journal* 323(7306), 178-179
- Crookes, P.A. (2010) 'The development of a ranking tool for refereed journals in which nursing and midwifery researchers publish their work'. *Nurse Education Today* 30(5), 420-427
- Dwyer, P. (2004) *Understanding Social Citizenship: Themes and Perspectives for Policy and Practice*. Bristol: Polity Press
- Fowler, M.D.M. (1989) 'Social advocacy'. *Heart and Lung* 18(1), 97-99
- French, S., Swain, J. (1999) *Therapy and Learning Difficulties: Advocacy, Participation and Partnership*. Oxford: Butterworth Heinemann

- French, S. and Swain, J. (2001) 'The relationship between disabled people and health and welfare professionals' Chapter 32 pp734-753 In Albrecht, G.L., Seelman, K.D. and Bury, M. [Eds] (2001) *Handbook of Disability Studies*. Thousand Oaks: Sage Publications
- Gallagher, H. (2001) 'What the Nazi Euthanasia program can tell us about disability oppression'. *Journal of Disability Policy Studies* 12(2), 96-99
- Gill, C. (2001) The social experience of disability. Chapter 13 pp351-372 In Albrecht, G.L., Seelman, K.D. Bury, M. [Eds] (2001) *Handbook of Disability Studies*. Thousand Oaks: Sage Publications
- Goggin, G. and Newell, C. (2005) *Disability in Australia. Exposing a Social Apartheid*. Sydney: UNSW Press
- Goodall, C. (1995) 'Is disability any business of nurse education?' *Nurse Education Today* 15(1), 323-327
- Goodley, D. and Lawthom, R. [Eds] (2006) *Disability and Psychology: Critical introductions and Reflections*. Houndmills: Palgrave
- Harrison, J. (1999) 'Health care access and equality for disabled people'. *British Journal of Therapy and Rehabilitation* 6(8), 380-383
- Harvey, L. (1990) *Critical Social Research. Contemporary Social Research*; 21. Boston: Unwin Hyman
- Johnson, P. & Buberley, J. (2003) *Understanding Management Research: An Introduction to Epistemology*. London: Sage
- Kane, A. and Gooding, C. (2009) *Reasonable adjustments in nursing and midwifery: A literature review*. London: Nursing and Midwifery Council
- Kellner, D. (1998) *Critical Theory, Marxism and Modernity*. Baltimore: Johns Hopkins University Press
- Kincheloe, J. and McLaren, P. (2005) Rethinking Critical Theory and Qualitative Research. Chapter 12 pp303-342 In Denzin, N. & Lincoln, N. (Eds.), *The Sage Handbook of Qualitative Research* (3rd ed) London: Sage
- Lewis, C. (2000) 'Disabled people, bioethics and human rights'. *Journal of Therapy and Rehabilitation* 7(5), 205
- Linton, S. (1998) 'Disability studies / not disability studies'. *Disability and Society* 13(4), 525-540
- Llewellyn, P. and Northway, R. (2007) 'An investigation into the advocacy role of the learning disability nurse'. *Journal of Research in Nursing* 12(2), 147-161
- Millington, P. and Mottram, R. (1999) 'Disability organizations and disability equality training'. *British Journal of Therapy and Rehabilitation* 6(8), 372-376
- Morrow, R. A. & Brown, D.D. (1994) 'Critical Theory and Methodology'. Volume 3, *Contemporary Social Theory*. Thousand Oaks: Sage
- Northway, R. (2000) 'Disability, nursing research and the importance of reflexivity'. *Journal of Advanced Nursing* 32(2), 391-397
- Northway, R. (2003) 'A question of rights'. *Learning Disability Practice* 6(6), 3-3

- Northway, R. (2010) 'Participatory research. Part 1: key features and underlying philosophy'. *International Journal of Therapy and Rehabilitation* 17(4), 174-179
- Oliver, M.J. (1999) 'The disability movement and the professions'. *British Journal of Therapy and Rehabilitation* 6(8), 377-379
- Oliver, M. (2009) *Understanding Disability; From Theory to Practice*. (2<sup>nd</sup> Ed.) Palgrave: Macmillan
- Pfeiffer, D. (2003) 'Attitudes towards disability in the helping professions'. *Disability Studies Quarterly* 23(2), 132-149
- Polit, D.F. and Beck, C.T. (2010) *Essentials of Nursing Research; Appraising Evidence for Nursing Practice*. (2nd Ed.) Philadelphia: Wolters Kluwer/ Lippincott Williams & Wilkins
- Porora, D.V. (2005) Do realists run regressions? Chapter 20 pp260-266 In Lopez, J. and Potter, G (eds.) *After Postmodernism: An Introduction to Critical Realism*. London: Consortium International Publishers
- Priestley, M. (1997) Who's research?: A personal audit. Chapter 6 pp 88-107, In *Doing Disability Research*. Barnes C, Mercer G, [Eds] Leeds: The Disability Press
- Priestley, M. (2003) *Disability; A Life Course Approach*. Cambridge: Polity
- Sandén, S. (2007) 'The Same Responsibilities - But Not The Same Rights, Citizenship as perceived and defined by disabled people; A Comparative study between the United Kingdom and Sweden'. Paper presented at the ESA 8th Conference, Glasgow. *Conflict, Citizenship and Civil Society*, September 5, 2007
- Scullion, P. (1995b) 'Oliver asks for more: rejecting illness, neglecting impairment, explaining disability and controlling rehabilitation'. *British Journal of Therapy and Rehabilitation* 2(10), 521-522
- Scullion, P. (2000a) 'Equity of access for disabled people'. *Professional Nurse* 15(10), 667-670
- Scullion, P. (2000b) 'Disability as an equal opportunity issue within nurse education in the UK'. *Nurse Education Today* 20(3), 199-206
- Scullion P (2000c) 'Enabling disabled people: responsibilities of nurse education'. *British Journal of Nursing* 9(15), 1010-1015
- Scullion, P. (2008a) 'A life unlike any other; human rights for some?' *British Journal of Nursing* 17(6), 354-355
- Scullion, P. (2008b) 'Disability equality and human rights: Are clients being empowered or impaired?' *International Journal of Therapy and Rehabilitation* 15(2), 58-9
- Scullion, P. (2009) 'An analysis of the 'Six disabled lives' in the UK: Important or impotent?' *International Journal of Therapy and Rehabilitation* 16(10), 522-523.
- Scullion, P., Brothers, M. and Eathorne, V. (2002) 'Education for all'. *Learning Disability Practice* 5(2), 8-10
- Scullion, P. A. (1995a) 'Disability research and health care professionals: some issues for debate'. *British Journal of Therapy and Rehabilitation* 2(6), 318-322

- Scullion, P. A. and Guest, D. A. (2007) *Study Skills for Nursing and Midwifery Students*. Maidenhead: McGraw-Hill with Open University Press
- Scullion, P. A. (2010a) 'Models of disability: their influence in nursing and potential role in challenging discrimination'. *Journal of Advanced Nursing* 66(3), 697-707
- Scullion, P. A. (2010b) 'Disability studies in health and nursing sciences: A wheel in one camp and one foot in the other'. *International Journal of Disability Studies* 4(1&2), 31-54
- Singer, P. (1994) *Rethinking Life & Death: The Collapse of Our Traditional Ethics* Oxford: Oxford University Press
- Smith, S.D., Reynolds C.A. and Rovnak, A. (2009) 'A critical analysis of the social advocacy movement in counselling'. *Journal of Counselling and Development* 87, 483-491
- Smith, S.R. (2005) 'Equality, identity and the disability rights movement: from policy to practice and from Kant to Nietzsche in more than one uneasy move'. *Critical Social Policy* 25(4), 554-576
- Stone, E. and Priestley, M. (1996) 'Parasites, pawns and partners: disability research and the role of non-disabled researchers'. *British Journal of Sociology* 47(4), 699-716
- Swain, J., Griffiths, C. and French, S. (2006) Counselling with the Social Model: Challenging Therapy's Pathologies. Chapter 11 pp155-169 In Goodley D, Lawthorn R [Eds] (2006) *Disability and Psychology: Critical introductions and Reflections*. Houndmills: Palgrave
- Swain, J., French, S. and Cameron, C. (2003) *Controversial Issues in a Disabling Society*. Buckingham: Open University Press
- Swain, J. (2006) 'Review of Disability rights in Europe: from theory to practice'. *Disability & Society* 21(3), 297-298
- Thomas, C. (2004) 'How is disability understood? An examination of sociological approaches'. *Disability & Society* 19(6), 570-583
- Thompson, N. (1998) *Promoting Equality: Challenging discrimination and oppression in the human services*. London: Macmillan
- Turner, B. S. (2008) *The Body and Society* (3<sup>rd</sup> Ed.) Sage: Los Angeles
- UK Disabled People's Council (2010) <http://www.ukdpc.net/index.asp?getpage=true&sid=66> (accessed June 4<sup>th</sup> 2010)
- Vanhala, L. (2006) 'Fighting discrimination through litigation in the UK: The social model of disability and the EU anti-discrimination directive'. *Disability & Society* 21(5), 551-565
- Williams G (2001) Theorizing disability, Chapter 4 pp123-144 In In Albrecht, G.L, Seelman, K.D. and Bury, M [Eds] (2001) *Handbook of Disability Studies*. Thousand Oaks: Sage Publications
- Yunker, H.E., Block, J.R. and Campbell, W.J. (1960) *A Scale to Measure Attitudes Towards Disabled Persons*. Human Resources Study Number 5. New York: Albertson Human Resources Centre

## Appendices

### Appendix 1

#### **List of six selected publications used as the basis for this portfolio**

##### Paper 1

Scullion P A (1999) 'Conceptualizing disability in nursing; some evidence from students and their teachers' *Journal of Advanced Nursing* 29(3), 648-657

##### Paper 2

Scullion P (1999) 'Disability' in a Nursing Curriculum'. *Disability and Society* 14(4), 539-559

##### Paper 3

Scullion P (1999) 'Challenging discrimination against disabled patients'. *Nursing Standard* 13(18), 37-40

##### Paper 4

Scullion P (2000) 'Disability as an equal opportunity issue within nurse education in the UK'. *Nurse Education Today* 20(3), 199-206

##### Paper 5

Scullion P (2000) 'Enabling disabled people: responsibilities of nurse education'. *British Journal of Nursing* 9(15), 1010-1015

##### Paper 6

Scullion, P. A. (2010) 'Models of disability: their influence in nursing and potential role in challenging discrimination'. *Journal of Advanced Nursing* 66(3), 697-707



Appendix 2**Comprehensive list of disability-related publications by this author  
excluding the six selected for this portfolio.**

Scullion P A (1995) Disability research and health care professionals: some issues for debate. British Journal of Therapy and Rehabilitation. 2;6, pp318-322. PR

Scullion P (1995) Oliver asks for more: rejecting illness, neglecting impairment, explaining disability and controlling rehabilitation. British Journal of Therapy and Rehabilitation. 2;10, pp521-522. E

Scullion P (1996) Dangerous images of disability. British Journal of Therapy and Rehabilitation. 3;4, pp186-188. E

Scullion P A (1996) Access for disabled people: applauding improvements. British Journal of Therapy and Rehabilitation. 3;7, pp356-357. E

Scullion P A (1996) 'Quasidisability' experiences using simulation. British Journal of Therapy and Rehabilitation. 3;9, pp498-502. PR

Scullion P A (1996) Making hospitals more 'user-friendly' for disabled people and their carers. Carers World. Sept./Oct., p28-29. NPR

Scullion P A (1996) Disability on the agenda. Elderly Care. 8;5, pp10-12. PR

Scullion P A (1997) What's in a word? PAL for people with a disability. British Journal of Therapy and Rehabilitation. 4;6, pp292-2. E

Scullion P A (1998). Recognising barriers to disabled people. British Journal of Nursing. 7;9, 509. E

Scullion P A (1998). Speaking Out. Nursing Times.95(7) 45. E

Scullion P (1999) An England coach and the public's attitude to 'people with disabilities'. British Journal of Therapy and Rehabilitation. 6(3) 108-109. PR

Scullion P (1999) Nurses can do it. Nursing Times. 95 (27) 28. E

Scullion P (1999) Conductive education, suspect and respect British Journal of Therapy and Rehabilitation. 6 ;7, 318-319. E

Scullion P (1999) Welcoming the enabling (21<sup>st</sup>) century. British Journal of Therapy and Rehabilitation. 6:8, 370-1. E

Scullion P (1999) Access denied? Royal College of Physicians helps open up hospitals. Ageing & Health. 5; pp23-24. NPR

Scullion P (2000) Disabling practice? Enabling nurses. *Nursing and Residential Care*. 2 (5) 235-239. NPR

Scullion P (2000) Implementing section 21 of the Disability Discrimination Act in the NHS, *British Journal of Therapy and Rehabilitation*. 7 (1), 5. E

Scullion P (2000) From Exclusion to Inclusion: a key role for rehabilitation staff. *British Journal of Therapy and Rehabilitation*. 7 (3) 105. E

Scullion P (2000) Anti-discriminatory practice: do health professionals need it? *British Journal of Therapy and Rehabilitation*. 7 (4) 157. E

Jayram R & Scullion P (2000) Access to all areas. *Nursing Management*. 7 (1) 17-19. PR

Scullion P & Jayram R (2000) Enabling Act. *Nursing Management*. 7 (2) 8-11. PR

Scullion P (2000) Disabled people as health service employees. *Nursing Management*. 7 (66) 8-13. NPR

Scullion P (2000) Serving and employing disabled people within the NHS. *British Journal of Therapy and Rehabilitation*. 7 (7) 314-318. PR

Scullion P (2000) Equity of access for disabled people. *Professional Nurse*. 15 (10) 667-670. PR

Scullion P (2001) 'The system': relating consumers' views to power and bureaucracy. *British Journal of Therapy and Rehabilitation*. 8;6, 205. E

Scullion P (2001) Bureaucratic barriers; new book, same old problems. *Pinpoint; The Magazine of Disability West Midlands*. New year edition. p10-11. NPR

Lee H, Scullion P (2001) De-medicalising disability. *Primary Health Care*. 11 (4) 29-32. PR

Scullion P (2001) Models of disability. *Primary Health Care*. 11 (4). 28-29. PR

Scullion P (2001) Home treatment service. *Primary Health Care*. 11 (5). 21-22. PR

Barlow J, Scullion P (2001) Self-management for 'expert-patients'. *British Journal of Therapy and Rehabilitation*. 8;7, 245. E

Scullion P & Eathorne V. (2001) Positive attitudes. Primary Health Care. 11 (7) 18. PR

Porter B, Scullion P (2001) Multiple sclerosis specialists: key to better services. British Journal of Therapy and Rehabilitation. 8;9, 325. E

Scullion P & Salley K (2001) From Coronary Care unit to community unit. Primary Health Care 11;(8) 37-38. E

Scullion P (2001) Royal College of Nursing. Muscle Power. Issue 33 Summer / Autumn 2001. pp14-16. NPR

Brothers M, Eathorne V, Scullion P (2002) Disability law and employment: what does it mean for staff? Residential and Nursing Care. 4,2 60-63. NPR

Scullion P, Brothers M, Eathorne V, (2002) Education for all. Learning Disability Practice. 5,2, 8-10. NPR

Scullion P (2002) Inclusive services: good practice for disabled clients. Primary Health Care. 12,6. 18-20. PR

Scullion P (2002) Neurological patients: the need for alliances. British Journal of Therapy and Rehabilitation. 9,8, 293. E

Brothers M, Scullion P, Eathorne V (2002) Rights of access to services for disabled people. British Journal of Therapy and Rehabilitation. 9,6, 232-236. PR

Scullion P A (2002) Effective dissemination strategies. Nurse Researcher. 10,1, 65-77. PR

Scullion P (2003) The decisions and dilemmas of dysphagia management. International Journal of Therapy and Rehabilitation. 10,5, 191. E

Scullion P (2003) Neurosciences forum goes live. Primary Health Care. 13,3, 14. E

Scullion P (2003) Empowering neurological patients. Primary Health Care. 13,7, 12. NPR

Scullion P (2004) Improving primary care services for disabled people- the legal leverage. Primary Health Care. 14,9, 18, 20. PR

Scullion P (2005) A new national service framework for rehabilitation. *International Journal of Therapy and Rehabilitation*. 12,4, 142. E

Scullion P (2006) Promoting equality through the amended Disability Discrimination Act. *International Journal of Therapy and Rehabilitation*. 13,5,196. E

Scullion P (2008) Disability equality and human rights: Are clients being empowered or impaired? *International Journal of Therapy and Rehabilitation*. 15, 2, 58-59. E

Scullion P (2008) A life unlike any other; human rights for some? *British Journal of Nursing*. 17, 6, 354-55. E

Scullion P (2009) An analysis of the 'Six disabled lives' in the UK: Important or impotent? *International Journal of Therapy and Rehabilitation*. 16, 10. 522-523. PR

Scullion P (2009) Economy and disability in Tokyo and Manchester. *International Journal of Therapy and Rehabilitation*. 16, 7. 385-390. E

Scullion P A (2010) Disability studies in health and nursing sciences: A wheel in one camp and one foot in the other. *International Journal of Disability Studies*. 4 (1&2) 31-54. *Also published as a Monograph; Scullion P A (2010) Disability Studies in Health and Nursing Sciences. Disability Studies in Higher Education; Monograph Series 3. Society for Disability and Rehabilitation Studies, New Delhi, India.* PR

PR – Peer Reviewed Journal

E- Editorial

NPR- Not Peer Reviewed or Uncertain

Appendix 3

**Hard copies of six publications selected for this portfolio**

Presented in numeric order

These papers are not included in the online version of this thesis due to third party copyright. The unabridged version of the thesis can be viewed at the Lanchester library, Coventry University.

#### Appendix 4

##### **Questions to be considered in relation to disability research.**

Taken from Table 1 (Scullion 1995a)

- Who stands to gain from this research or proposal?
- What definitions are utilised and how do these link with conceptual model of disability?
- How accurately do the measures used match the phenomena being studied?
- Are there assumptions left unchallenged by this research?
- What role is there for disabled people to participate or validate the research?
- What essentially is going on?
- Why has this been the case historically?
- What structures reproduce this state of affairs?

Appendix 5**Citations of selected publications**

Papers presented in order; citations most recent first.

**PAPER ONE: Scullion P A (1999) Conceptualizing disability in nursing; some evidence from students and their teachers. Journal of Advanced Nursing. 29 (3) 648-657**

Ten Klooster, P.M., Dannenberg, J.-W., Taal, E., Burger, G., Rasker, J.J. (2009) Attitudes towards people with physical or intellectual disabilities: Nursing students and non-nursing peers Journal of Advanced Nursing, 65 (12), pp. 2562-2573.

Aphramor, L. (2009) Disability and the anti-obesity offensive Disability and Society, 24 (7), pp. 897-909.

Lewis, J.L. (2009) Student attitudes toward impairment and accessibility: An evaluation of awareness training for urban planning students Vocations and Learning, 2 (2), pp. 109-125.

Ashcroft, T.J., Chernomas, W.M., Davis, P.L., Dean, R.A.K., Seguire, M., Shapiro, C.R., Swiderski, L.M. (2008) Nursing students with disabilities: One faculty's journey. International Journal of Nursing Education Scholarship, 5 (1), art. no. 18.

Boyles, C.M., Bailey, P.H., Mossey, S. (2008) Representations of disability in nursing and healthcare literature: An integrative review. Journal of Advanced Nursing, 62 (4), pp. 428-437.

Kontosh, L.G., Fletcher, I., Frain, M., Winland-Brown, J. (2007) Work place issues surrounding healthcare professionals with disabilities in the current labor market Work, 29 (4), pp. 295-302.

Smeltzer, S.C. (2007) Improving the health and wellness of persons with disabilities: A call to action too important for nursing to ignore. Nursing Outlook, 55 (4), pp. 189-195.

Seccombe, J.A. (2007) Attitudes towards disability in an undergraduate nursing curriculum: A literature review. Nurse Education Today, 27 (5), pp. 459-465.

Marks, B. (2007) Cultural competence revisited: Nursing students with disabilities. Journal of Nursing Education, 46 (2), pp. 70-74.

Honey, M., Waterworth, S., Baker, H., Lenzie-Smith, K. (2006) Reflection in the disability education of undergraduate nurses: An effective learning tool? Journal of Nursing Education, 45 (11), pp. 449-453.

Evans, B.C. (2005) Nursing education for students with disabilities: Our students, our teachers. *Annual Review of Nursing Education*, 3, pp. 3-22.

Hassouneh-Phillips, D., McNeff, E., Powers, L., Curry, M.A. (2005) Invalidation: A central process underlying maltreatment of women with disabilities. *Women and Health*, 41 (1), pp. 33-50.

Smeltzer, S.C., Dolen, M.A., Robinson-Smith, G., Zimmerman, V. (2005) Integration of disability-related content in nursing curricula. *Nursing Education Perspectives*, 26 (4), pp. 210-216.

Carroll, S.M. (2004) Inclusion of people with physical disabilities in nursing education. *Journal of Nursing Education*, 43 (5), pp. 207-212.

Kearney, P.M., Pryor, J. (2004) The International Classification of Functioning, Disability and Health (ICF) and nursing. *Journal of Advanced Nursing*, 46 (2), pp. 162-170.

Northway, R. (2003) Meaning of life for adolescents with a physical disability in Korea: Commentary. *Journal of Advanced Nursing*, 43 (2), pp. 155-157.

Hahn, J.E.(2003) Addressing the need for education: Curriculum development for nurses about intellectual and developmental disabilities. *Nursing Clinics of North America*, 38 (2), pp. 185-204.

Treloar, L.L. (2002) Disability, spiritual beliefs and the church: The experiences of adults with disabilities and family members. *Journal of Advanced Nursing*, 40 (5), pp. 594-603.

Kearney, P.M., Griffin, T. (2001) Between joy and sorrow: Being a parent of a child with developmental disability. *Journal of Advanced Nursing*, 34 (5), pp. 582-592.

Bricher, G. (2000) Disabled People, Health Professionals and the Social Model of Disability: Can there be a research relationship? *Disability and Society*, 15 (5), pp. 781-793.

Northway, R. (2000) Disability, nursing research and the importance of reflexivity. *Journal of Advanced Nursing*, 32 (2), pp. 391-397.

Scullion, P. (2000) Disability as an equal opportunity issue within nurse education in the UK. *Nurse Education Today*, 20 (3), pp. 199-206.



**PAPER 2: Scullion P (1999) 'Disability' in a Nursing Curriculum. Disability and Society. 14(4) 539-559.**

Sahin, H., Akyol, A. D. (2010) Evaluation of nursing and medical students' attitudes towards people with disabilities. *Journal of Clinical Nursing*, 19 (15/16), pp. 2271-2279.

Scullion, P.A. (2010) Models of disability: Their influence in nursing and potential role in challenging discrimination. *Journal of Advanced Nursing*, 66 (3), pp. 697-707.

Campbell, F.K. (2009) Medical education and disability studies. *Journal of Medical Humanities*, 30 (4), pp. 221-235.

Schweik S (2009) *The Ugly Laws: Disability in Public*. New York. New York University Press.

Boyles, C.M., Bailey, P.H., Mossey, S. (2008) Representations of disability in nursing and healthcare literature: An integrative review. *Journal of Advanced Nursing*, 62 (4), pp. 428-437.

Secombe, J.A. (2007) Attitudes towards disability in an undergraduate nursing curriculum: A literature review. *Nurse Education Today*, 27 (5), pp. 459-465.

Johnson, K, Strong, R. Hillier, L. Pitts, M (2006) Screened Out: Women with Disabilities and Preventive Health. *Scandinavian Journal of Disability Research*. 8 (2-3), pp. 150-160.

Hubbard, S. (2004) Disability studies and health care curriculum: The great divide. *Journal of Allied Health*, 33 (3), pp. 184-188.

Iacono, T., Davis, R. (2003) The experiences of people with developmental disability in Emergency Departments and hospital wards. *Research in Developmental Disabilities*, 24 (4), pp. 247-264.

Johnson, K, Strong, R. Hillier, L. Pitts, M (2002) Screened Out: Women with Disabilities and Cervical Screening. The Cancer Council Victoria. Australian Research Centre in Sex Health and Society, La Trobe University [also available online at [www.papscreen.org](http://www.papscreen.org)]

Pfeiffer, D. (2001) The Conceptualization of Disability. *Research in Social Science and Disability*, 2, pp.29-52.

Newell, C. (2000) Biomedicine, genetics and disability: reflections on nursing and a philosophy of holism. *Nursing Ethics*, 7 (3), pp. 227-236.

**PAPER 3: Scullion P (1999) Challenging discrimination against disabled patients. Nursing Standard. 13,18, 37-40**

Scullion, P.A. (2010) Models of disability: Their influence in nursing and potential role in challenging discrimination. *Journal of Advanced Nursing*, 66 (3), pp. 697-707.

Watermeyer, B.P. (2009) Conceptualising psycho-emotional aspects of disablist discrimination and impairment: towards a psychoanalytically informed disability studies. Dissertation presented for the degree of Doctor of Philosophy in the Department of Psychology. Stellenbosch University, South Africa.

Sheerin F. K. (2008) Diagnoses and Interventions Pertinent to Intellectual Disability Nursing. *International Journal of Nursing Terminologies and Classifications*, 19 (4), pp. 140-149.

Marks, B. (2007) Cultural competence revisited: Nursing students with disabilities. *Journal of Nursing Education*, 46 (2), pp. 70-74.

Engler M B (2007) School of Nursing Faculty Council Annual Report 2006-2007, University of California, San Francisco. [Available online at [www.ucsf.edu/senate](http://www.ucsf.edu/senate)].

Smeltzer, S.C., Dolen, M.A., Robinson-Smith, G., Zimmerman, V. (2005) Integration of disability-related content in nursing curricula. *Nursing Education Perspectives*, 26 (4), pp. 210-216.

Smeltzer, S.C., Zimmerman, V., Frain, M., DeSilets, L., Duffin, J. (2004) Accessible online health promotion information for persons with disabilities. *Online Journal of Issues in Nursing*, 9 (1), pp. 96-113.

Konur, O. (2002) Access to nursing education by disabled students: Rights and duties of nursing programs. *Nurse Education Today*, 22 (5), pp. 364-374.

Building Bridges (2002) Building Bridges Across Difference and Disability; A Resource Guide for Health Care Providers. Ontario. AboutFace International and the Body Image Project, Regional Women's Health Centre, Sunnybrook and Women's College Health Sciences Centre, Canada.

Basnett, I. (2001) Health care professionals and their attitudes toward and decisions affecting disabled people. Chapter 18, pp.450-467 In Albrecht, G.L, Seelman, K.D. and Bury, M [Eds] (2001) *Handbook of Disability Studies*. Thousand Oaks: Sage Publications.

Northway, R. (2000) Disability, nursing research and the importance of reflexivity. *Journal of Advanced Nursing*, 32 (2), pp. 391-397.

Scullion, P. (2000) Disability as an equal opportunity issue within nurse education in the UK. *Nurse Education Today*, 20 (3), pp. 199-206.

In addition one paper was located in Turkish and one paper in Chinese.

**PAPER 4: Scullion P (2000) Disability as an equal opportunity issue within nurse education in the UK. Nurse Education Today. 20 199-206.**

Matthews, N. (2010) Anxiety and niceness: Drawing disability studies into the art and design curriculum through a live brief. *Macquarie University, Australia* Online Available at [http://74.125.155.132/scholar?q=cache:ufuTiA8JfuEJ:scholar.google.com/&hl=en&as\\_sdt=2000](http://74.125.155.132/scholar?q=cache:ufuTiA8JfuEJ:scholar.google.com/&hl=en&as_sdt=2000)

Scullion, P.A. (2010) Models of disability: Their influence in nursing and potential role in challenging discrimination. *Journal of Advanced Nursing*, 66 (3), pp. 697-707.

Matthews, N. (2009) Teaching the 'invisible' disabled students in the classroom: Disclosure, inclusion and the social model of disability. *Teaching in Higher Education*, 14 (3), pp. 229-239.

Bheenuck, S., Miers, M., Pollard, K., Young, P. (2007) Race equality education: Implications of an audit of student learning. *Nurse Education Today*, 27 (5), pp. 396-405.

Peckover, S., Chidlaw, R.G. (2007) Too frightened to care? Accounts by district nurses working with clients who misuse substances. *Health and Social Care in the Community*, 15 (3), pp. 238-245.

Marks, B. (2007) Cultural competence revisited: Nursing students with disabilities. *Journal of Nursing Education*, 46 (2), pp. 70-74.

Konur, O. (2002) Access to nursing education by disabled students: Rights and duties of nursing programs. *Nurse Education Today*, 22 (5), pp. 364-374.

El Ansari, W. (2002) Student nurse satisfaction levels with their courses: Part I - Effects of demographic variables. *Nurse Education Today*, 22 (2), pp. 159-170.

Pfeiffer D (2001) A Pessimistic Finding Regarding Faculty Affirmative Action in Higher Education. Centre on Disability Studies University of Hawaii at Manoa.

**PAPER 5: Scullion P (2000) Enabling disabled people: responsibilities of nurse education. British Journal of Nursing. 9 (15) 1010-1015.**

Scullion, P.A. (2010) Models of disability: Their influence in nursing and potential role in challenging discrimination. *Journal of Advanced Nursing*, 66 (3), pp. 697-707.

Matziou, V., Galanis, P., Tsoumakas, C., Gymnopoulou, E., Perdikaris, P., Brokalaki, H. (2009) Attitudes of nurse professionals and nursing students towards children with disabilities. Do nurses really overcome children's physical and mental handicaps?: Original Article. *International Nursing Review*, 56 (4), pp. 456-460.

Seccombe, J.A. (2007) Attitudes towards disability in an undergraduate nursing curriculum: The effects of a curriculum change. *Nurse Education Today*, 27 (5), pp. 445-451.

Seccombe, J.A. (2007) Attitudes towards disability in an undergraduate nursing curriculum: A literature review. *Nurse Education Today*, 27 (5), pp. 459-465.

Smeltzer, S.C. (2007) Improving the health and wellness of persons with disabilities: A call to action too important for nursing to ignore. *Nursing Outlook*, 55 (4), pp. 189-195.e2.

Smeltzer, S.C., Dolen, M.A., Robinson-Smith, G., Zimmerman, V. (2005) Integration of disability-related content in nursing curricula. *Nursing Education Perspectives*, 26 (4), pp. 210-216.

Melville, C. (2005) Discrimination and health inequalities experienced by disabled people. *Medical Education*, 39 (2), pp. 124-126.

Kendall, M.B., Ungerer, G., Dorsett, P. (2003) Bridging the gap: Transitional rehabilitation services for people with spinal cord injury. *Disability and Rehabilitation*, 25 (17), pp. 1008-1015.

van Erp, Ansmarie (2002) A life changing experience - a rural perspective on living with physical disability. (Unpublished PhD Thesis). University of Southern Queensland.

McLeod, D, Cormack, D, Kake, T (2001) The Health Needs of the Children of Operation Grapple and Vietnam Veterans. A Critical Appraisal Undertaken for the Office of Veterans' Affairs, Ministry of Defence. New Zealand. Available online at: <http://media.apn.co.nz/webcontent/document/pdf/mcleodreport.pdf>

Appendix 6

**Table 6 Elegant Challenging from Thompson 1998**

[as adapted in Scullion (2000) Paper five]

- Being constructive and tactful rather than personal
- Avoiding cornering people
- Being appropriate in time and place
- Avoiding unnecessary hostility
- Acknowledging the possibility of 'bad practice' in those who mount the challenge
- Presenting a spirit of compassion and commitment to social justice

Appendix 7**Indicators of Esteem**

- **Reviewer** of bids for Department of Health funding of projects associated with the National Service Framework for Long Term Condition. 2005, 2008 & 2010
- **Editorial Board Member** -International Journal of Disability Studies and International Journal of Therapy and Rehabilitation.
- **Reviewer** for Journal of Advanced Nursing and Nurse Education Today (formerly also for Nursing Standard, Professional Nurse, Primary Health Care)
- **Reviewer for the curriculum framework** for teaching disability equality to healthcare students, outcome of a HEFCE funded project; Disability Equality-Centre for Medical Education. Partners in Practice; collaboration between University of Bristol and the West of England and Peninsula Medical School [July 2005]
  
- **Presented key-note address** 'Just Two Ticks' to Cornwall Health and Social Care Disability Awareness conference, Bodmin. 2001.
- **Organised and presented** at 'Disabling Practice? Enabling Nurses' - Staffordshire Disability Awareness, Post Graduate Medical Centre, Staffordshire General Hospital Stafford, 2001.
- **Presented paper** Annual Conference of the International Society for Disability Studies, Oakland USA. 2002
- **Invited lecture** 'Disability Studies', Jawaharlal Nehru University, New Delhi, India. 2008.
- **Paper accepted** for 2010 UK Disability Studies Conference, Lancaster University- and chairing sessions.
  
- **Chair of National Neurosciences Forum**- Royal College of Nursing, 2002-2004.
- **Instrumental in establishing** the RCN Neurosciences Nursing Forum while employed by Royal College of Nursing.
- **Member of Advisory Panel** to ESF Project 'Discrimination in the workplace: Older nurses in the NHS' University of Hull. [2004-2006]
- **Advisory Group Member** for Disability Rights Commission funded research; 'Research into assessments and decisions relating to 'fitness' in training, qualifying and working within Teaching, Nursing and Social Work', Jane Wray, Helen Gibson and Jo Aspland University of Hull. [March 2007]

- **Cited extensively** by Local Government Association / Deputy Prime Ministers' office document regarding the inclusion of fire-fighters in the provision of the Disability Discrimination Act; in relation to models of disability (Scullion 2001)

This 103 page document provides guidance which is intended to provide information and advice to Fire and Rescue Services in England, Wales, Scotland and Northern Ireland on the implementation of Part 2 the Disability Discrimination Act (DDA) 1995 as it applies to fire-fighters conditioned to the whole time and retained duty systems. *Scullion P (2001) 'Models of Disability' in Primary Health Care*  
[http://www.nifrs.org/docs/uploaded/Fire\\_Service\\_Guidance.pdf](http://www.nifrs.org/docs/uploaded/Fire_Service_Guidance.pdf)  
Accessed 30<sup>th</sup> June 2010

- **Contributed to Motor Neurone Disease Pain Pathway** (Specialist nurses)

<http://www.redpublish.co.uk/wp-content/uploads/2009/03/pain-pathway.pdf>  
and

- **Parkinson's Disease Specialist Nurses Competencies booklet** (Royal College of Nursing)
- Held **External Examiner** posts at Leeds University and University of Manchester
- Regular **book reviewer**; often on disability related topics e.g. 'Disability Sport and Society', by Nigel Thompson and Andy Smith, 2009, review published in International Journal of Therapy and Rehabilitation. 16 (8) p461.
- Scullion, P. (1996). Quasidisability experiences using simulation. *British Journal of Therapy and Rehabilitation*, 4, 292-293. **Cited in The Review of Disability Studies: An International Journal.**

<http://www.rds.hawaii.edu/downloads/issues/pdf/RDSissue022004.pdf>

and Sheryl Burgstahler, Ph.D. and Tanis Doe, Ph.D. University of Washington Disability-related Simulations: If, When, and How to Use Them in Professional Development In Burgstahler, S., & Doe, T. (2004). Disability-related simulations: If, when, and how to use them. *Review of Disability Studies*, 1(2), 4-17.

<http://staff.washington.edu/sherylb/RDSissue022004.pdf>  
<http://staff.washington.edu/sherylb/RDSissue022004.html>